



Feature Article

Justifying continuous sedation until death: A focus group study in nursing homes in Flanders, Belgium

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ARTICLE INFO

Article history:

Received 17 July 2012

Received in revised form

18 October 2012

Accepted 22 October 2012

Available online 28 December 2012

Keywords:

Continuous sedation

Terminal sedation

Palliative sedation

Ethics

Nursing homes

Palliative care

End of life care

Focus groups

ABSTRACT

Continuous Sedation until Death (CSD), the act of reducing or removing the consciousness of an incurably ill patient until death, has become a common practice in nursing homes in Flanders (Belgium). Quantitative research has suggested that CSD is not always properly applied. This qualitative study aims to explore and describe the circumstances under which nursing home clinicians consider CSD to be justified. Six focus groups were conducted including 10 physicians, 24 nurses, and 14 care assistants working in either Catholic or non-Catholic nursing homes of varying size. Refractory suffering, limited life expectancy and respecting patient autonomy are considered essential elements in deciding for CSD. However, multiple factors complicate the care of nursing home residents at the end of life, and often hinder clinicians from putting these elements into practice. Nursing home clinicians may benefit from more information and instruction about managing CSD in the complex care situations which typically occur in nursing homes.

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1. Introduction

Sedating a terminally ill patient to relieve distress has become a common practice in end-of-life care.¹ Guidelines on this practice, often referred to as palliative sedation, have been published worldwide.^{2–6} Most guidelines describe two types of palliative sedation: intermittent and continuous sedation. The depth of sedation can vary from a lowered state of consciousness to unconsciousness. In this study we focus on the practice of Continuous Sedation until Death (CSD), where an incurably ill patient is kept unconscious until death.

As is the case in many care settings, CSD has increasingly become a common practice in nursing homes in Flanders, Belgium, where the rate of CSD rose from 2.9% of all deaths in 2001 to 9.4% in 2007.⁷ Furthermore, in most of these cases, artificial nutrition and hydration were withheld, and the informed consent of the patient

lacking. In 12% of these cases the physician reported a co-intention, and in 1% an explicit intention to hasten death. Additionally, in 15% of the cases alternatives to CSD were available to control suffering.

However, in the published guidelines on CSD, obtaining informed consent and the absence of an intention to hasten death are considered important requirements for CSD. These guidelines also emphasize that CSD is only justified for the relief of refractory suffering, as a treatment of last resort, and provided that the patient has a limited life expectancy.

The differences between guideline recommendations and clinical practice potentially suggest that CSD is not always being appropriately applied in nursing homes in Flanders. The aforementioned Belgian quantitative study describes certain aspects of the practice of CSD in nursing homes, but does not clarify why several guideline recommendations were not followed in a substantial number of cases. Obviously, the non-adherence to guidelines—not only in nursing homes but in all care settings—has become a matter of concern in Flanders, Belgium.⁸ This study aims to explore and describe the circumstances under which nursing home clinicians (physicians, nurses, and care assistants) consider CSD to be justified. In doing so, this study hopes to

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provide a better understanding of the gap between guidelines and clinical practice.

2. Methods

2.1. Study design and setting

This study used a qualitative design, based on a thematic content analysis of focus group interviews with physicians, nurses, and care assistants working in nursing homes in Flanders, Belgium.

In Flanders, nursing homes are care settings that provide skilled nursing care to elderly people with disabilities in their activities of daily living, but who do not need constant medical supervision. Physicians are not continuously present in the nursing homes. Medical supervision is mostly given by the regular general practitioners of the nursing home residents. On the other hand, each nursing home is legally required to have one coordinating and advisory physician. This is a general physician, preferably experienced and trained in gerontology and palliative care, who is responsible for the coordination of medical activities in the nursing home, for the training of nursing home staff, and the development of (training for) palliative care. Coordinating and advisory physicians may also intervene in individual end-of-life care situations, e.g. to offer support and consultancy. They are also responsible for the medical treatment of residents without a regular general practitioner. Nursing home staff largely consists of nurses and care assistants, although some (large) nursing homes can also employ a physiotherapist, a social worker, a psychologist, a moral consultant or pastor. Head nurses are in charge of the different wards of a nursing home, whereas the coordinating nurse has a managing role throughout the entire nursing home.

2.2. Planning of focus groups and recruitment of participants

To maximize the relevance and variety of the obtained information, the organization of focus groups and the recruitment of focus group participants were conducted through different modes. Since it is possible that the size, religious affiliation or location of nursing homes may influence the attitudes and knowledge of CSD among clinicians, e.g. through the prevalence and content of written (ethics) policies on end-of-life care, we decided to organize focus groups in both Catholic as well as non-Catholic nursing homes of varying size and located in different regions in Flanders (urban and rural). Initially, we planned focus groups in 4 different nursing homes: a small Catholic nursing home, a large Catholic nursing home, a small private (non-Catholic) nursing home, and a large public (non-Catholic) nursing home. Eligible institutions were identified through key informants (practicing nurses and physicians). Consequently, these institutions were contacted by telephone to assess their willingness to participate in our study. Two institutions refused because of the workload. In these cases, we contacted other nursing homes with the same selected characteristics (religious affiliation, size, and region). Subsequently, arrangements were made with the coordinating nurses regarding

the compositions of the focus groups. The recruitment of participants within each institution was carried out by the coordinating nurse and guided by the following inclusion criteria: 1) having taken care of several dying nursing home residents, 2) willingness to participate. Careful consideration was also given to the size of the focus groups (6–10 persons), and the proportions of the different professions (physicians, nurses, and care assistants). In two nursing homes, we invited the coordinating and advisory physician to participate in the focus group discussion. However, because it was unclear to what extent the presence of this physician, as a potential authority figure, influenced free responses of nurses and care assistants, we also organized two focus group discussions without the coordinating and advisory physician.

The research protocol was approved by the Ethical Committee of UZ Brussel (reference 2010/284). A signed informed consent was obtained from each participant before each focus group interview.

After having conducted the focus group interviews in four different types of nursing homes, we felt that general practitioners were underrepresented in our study. Therefore, we organized an additional focus group discussion with only general practitioners of residents of a variety of nursing homes. This focus group took place outside the nursing homes. These physicians were recruited through a local consultation committee of general practitioners, which is a peer group that regularly meets to discuss and improve the quality of primary medical care. However, this focus group did not result in the identification of new findings, suggesting that a high degree of saturation had been reached. Consequently, one last focus group was conducted to confirm that saturation had indeed been achieved regarding the key questions. This focus group took place in a large non-Catholic nursing home and was attended by the coordinating and advisory physician. An overview of the characteristics of the different focus groups can be found in Table 1, while the selected characteristics of the participants and nursing homes are listed in Table 2.

2.3. Data collection

The focus groups took place from November 2010 till May 2011. Each focus group interview was conducted in a quiet meeting room, digitally recorded, and lasted between 90 and 120 min. At the start of each focus group, the participants were briefed about some important 'ground rules' of a focus group discussion, e.g. no talking through each other, keeping the information discussed confidential, and so on. The discussions were moderated by a researcher (SR), using a semi-structured interview guide that was developed through a review of the literature and guidelines on CSD (Table 3). This interview guide ensured consistency of the key questions asked across the different groups, but also allowed the moderator to explore certain aspects in more depth as well.⁹ The practice of CSD was introduced by the moderator and defined as the act of removing the consciousness of an incurably ill patient until death. An additional researcher (RD or CB) attended each focus group to observe the discussions and make notes. The observing researcher was also given the possibility of asking additional questions. In

Table 1
Characteristics of the focus groups ($n = 6$).

	Catholic nursing homes	Non-Catholic nursing homes
≥90 beds	1 mixed group consisting of nursing home staff and the coordinating and advisory physician ($n = 10$)	1 group consisting of only nursing staff ($n = 9$) 1 mixed group consisting of nursing home staff and the coordinating and advisory physician ($n = 7$)
<90 beds	1 group consisting of only nursing staff ($n = 7$)	1 mixed group consisting of nursing home staff and the coordinating and advisory physician ($n = 8$)
Organized outside a nursing home	1 group consisting of only physicians ($n = 7$)	

Table 2Selected characteristics of focus group participants and nursing homes ($n = 48$).

	Frequency (n)	Percent
Profession		
Coordinating and advisory physician	5	10.4
General physician	5	10.4
Coordinating nurse	4	8.3
Head nurse	7	14.6
Nurse	13	27.1
Care assistant	12	25
Other ^a	2	4.2
Sex		
Male	15	31.3
Female	33	68.8
Age		
30–40	12	25
41–50	18	37.5
51–60	16	33.3
>61	2	4.2
Work experience		
<5 years	3	6.3
5–10 years	4	8.3
11–20 years	16	33.3
21–30 years	12	25
>30 years	13	27.1
Training in palliative care ^b		
Yes, postgraduate degree	8	17
Yes, training	34	72.3
No	5	10.6
Type of nursing home ^c		
Non-Catholic	24	58.5
Catholic	17	41.5
Size of nursing home ^c		
Large (≥ 90 beds)	26	63.4
Small (< 90 beds)	15	36.6
Total	48	100

^a One psychologist and one pastor. These persons are full members of their respective palliative care teams.

^b One value missing.

^c Focus group with only physicians excluded.

doing so, information could be collected and interpreted through different viewpoints. Immediately after each focus group interview, both researchers discussed the outcomes and overall impressions of the discussions. Subsequently, the interviews were transcribed verbatim. The participants' names were replaced by fictive names and any other information that could lead to identification was removed from the transcripts. Between each focus group, two researchers (SR & RD) read through the transcripts to identify and discuss predominant themes. This way, preliminary findings could be examined in the following focus group interview.

2.4. Analysis

All the interview transcripts were imported in NVivo 8. To enhance the confirmability of the findings, three researchers—a nurse/health scientist (SR), an anthropologist/professor in qualitative research (RD), and a public health scientist (CB)—analyzed thoroughly and independently a random sample of two focus group

transcripts through an open coding method.¹⁰ Relevant text passages were considered as *meaning units*.¹¹ These *meaning units* were constantly compared with each other for possible similarities and were then grouped to form first-level codes, i.e. *condensed meaning units*. After analyzing the random sample of transcripts, the researchers met to discuss the definition and application of the *condensed meaning units* that were found. Consequently, the *condensed meaning units* were abstracted and grouped under higher order headings, namely *themes*. Table 4 shows examples of a meaning unit, a condensed meaning unit, and a theme. In this way, a hierarchical coding structure was developed. Once the basic coding structure was established, all interview transcripts were encoded by one researcher (SR). During this coding process regular meetings were held with the researchers involved to discuss the codes and corresponding quotes until consensus was reached.

3. Results

The following themes—with regard to the conditions under which nursing home clinicians consider CSD to be justified—emerged from the focus group discussions: refractory suffering, limited life expectancy, artificial nutrition and hydration, autonomy, proportional dosages and intentions.

3.1. Refractory suffering

When they were asked under what circumstances they would consider CSD, all focus group participants initially described situations of refractory suffering, situations where conventional symptom management has failed.

“In my opinion, one should turn to palliative sedation only after you’ve explored all the other possible options. But these other options must be ruled out first.” (Leona, head nurse)

CSD is also considered to be justified in situations where unbearable suffering has a psychosocial or existential nature.

“Psychic unrest, if you can’t control that ... I think that that can be worse than actual pain.” (Greta, head nurse)

To determine the degree of suffering by refractory symptoms, physicians consider the opinion of capable nursing home residents as most reliable source.

“And we don’t feel what they feel. We shouldn’t start to judge.” (Freya, nurse)

Nevertheless, many nursing home residents have dementia, which may seriously impede the evaluation of suffering.

“Definitely in a dementia ward, that’s about as hard as it gets. One day it’s like this and the other day is completely different. Then it’s very hard to make an assessment” (Nancy, care assistant)

Table 3

Content of the semi-structured interview guide.

Interview question	Key probes ^a
When is it justified to administer continuous sedation until death?	<ul style="list-style-type: none"> Under what circumstances would you consider administering CSD a therapy of last resort? How do you deal with the decision-making process (cf. informed consent, patient request, incompetence)? Is it only justified for patients who have already begun the process of dying? How do you deal with (artificial) nutrition and hydration? How do you determine the dosage of drugs? What is your opinion on the administration of CSD with the intention of shortening life?

^a These probes were asked depending on the spontaneous answers, not necessarily in the order and wording presented in this table.

Table 4

Example of a meaning unit, a condensed meaning unit, and a theme.

Meaning unit	Condensed meaning unit	Theme
<i>"If the intent is to remove consciousness, strictly speaking, you must have an informed consent."</i> (Mark, general physician)	Informed consent	Autonomy

3.2. Limited life expectancy

In general, CSD is considered to be justified only for patients who are close to death.

"Of course, the patient has to be in the dying phase." (Babette, coordinating nurse)

A few clinicians, however, would not exclude residents with a relatively long life expectancy.

Sam, researcher: *"And in patients with a longer life expectancy, that have maybe 6–7 months to live, and can still eat? Would palliative sedation be appropriate then?"*

Leona, head nurse: *"Certainly, we've been in the situation before. In the end, the woman said 'No let's wait a while longer'."*

Physicians also believe that a long survival contributes to a long period of sedation, which may cause pharmacological problems, i.e. the development of tolerance to sedative drugs.

"After a while you just notice that they have developed a tolerance to the drug, and that they are no longer under sedation. The muscles are unresponsive, but we can no longer speak of sedation. [...] I would be careful, only in residents with a few weeks left to live, but not months". (Jurgen, coordinating and advisory physician)

Furthermore, clinicians describe how they often feel pressure from the patient's family, when CSD takes too long.

"The problem is that if the palliative sedation takes too long, the family starts to ask 'How long is this going to take?'" (Bauke, head nurse)

Overall, all clinicians find it hard to predict the life expectancy of nursing home residents. Frequently, nursing home residents survive much longer than expected.

"A while ago, I had a patient in very bad condition ... He could no longer drink or speak ... 89 years old, with a tumor. I was going on holiday and I didn't expect to see him again after my holiday, so I took leave of him. But when I came back, 3 weeks later, that man was still alive, and able to talk again! Sometimes you're really surprised!" (Jurgen, coordinating and advisory physician)

3.3. Artificial nutrition and hydration

The question whether to withhold artificial nutrition and hydration rarely arises in nursing homes. Generally, nursing home residents have, in the process of dying, already stopped eating and drinking. The focus group participants all feel that they should not intervene in this natural process. Because artificial nutrition and hydration might prolong the course of suffering and the process of dying, the combination of CSD and artificial nutrition and hydration is found to be contradictory and ethically indefensible.

"With us, it happens more gradually. People start to deteriorate, and at a certain moment they can no longer eat, and they can no longer drink ... so it follows a very natural process." (Leona, head nurse)

"I don't see the point in removing the patient's consciousness, so that he doesn't have to experience his dying process, but then on the other hand still administering artificial hydration to prolong the

dying process. To me, this is ethically indefensible, it's a contradiction." (Romain, coordinating and advisory physician)

However, nurses and care assistants are sometimes confronted with the fact that residents are hospitalized when their condition becomes aggravated. Occasionally, these patients return from the hospital with a feeding tube. In these cases, they find it hard to withdraw tube-feeding.

"But I have the feeling that it makes the whole thing more difficult. [it's easier] if the person in question indicates that they no longer want to eat or drink anymore. But if you have to take out a feeding tube, then that is more ... it's not so easy to ... then you have to make a decision ..." (Stephanie, coordinating nurse)

3.4. Autonomy

All participants stress that respecting the patient's wishes is a matter of major concern in deciding for CSD. Obtaining informed consent is seen as a prerequisite for starting CSD.

"If the intent is to remove consciousness, strictly speaking, you must have an informed consent." (Mark, general physician)

Most clinicians tend to grant clear requests for CSD made by nursing home residents with the mental capacity for taking such decisions. Even in the absence of physical refractory suffering, such requests would be seriously considered, although an immediate administration of CSD is not probable.

"But if the resident is still in good condition, and says 'I'm 90 years old and my life has been good, and now I want to end it'. So automatically he will stop eating, this is a decision he will make himself, and then obviously symptoms will begin to manifest. And then, according to me, you will respond to those symptoms. And in such a context, sedation might be appropriate." (Jan, head nurse)

However, it must be noted that the majority of nursing home residents in Flanders, Belgium, have dementia. In these cases, it is impossible to obtain informed consent. Therefore, clinicians often involve the patients' representatives (mostly family members) in the decision-making process.

"Severely demented patients, who are writhing in pain, but who cannot decide for themselves. Then I find that, in dialogue with the legal representative, sedation has to be an option. It would be negligent to let people continue suffering from the pain." (Romain, coordinating and advisory physician)

Still, involving family members may cause difficulties. As mentioned before, the family may put pressure on physicians and nurses to accelerate the dying process. The contrary, situations where family members insist on starting life prolonging treatments, also occurs.

"We will not increase the dosage if the symptoms are under control, but every once in a while you feel pressured by 'the patients context' [the patient's family]: 'this has already taken 2 weeks, how much longer is this going to last?'" (Ronald, coordinating nurse)

"It's then that the family sometimes mentions 'Shouldn't we bring her to the hospital, because she is dehydrating'. Because all of a sudden they realise 'We can't let this happen to our mother'. Then they want to take her to the hospital." (Adelheid, head nurse)

3.5. Proportional dosages and intentions

Most clinicians agree in principle with the guideline that the level of sedation should be proportional to the level of suffering, in order to lower the risk of hastening death. However, they often find it difficult to titrate sedatives. On the other hand, some clinicians do

not see the point of titrating sedatives; they prefer deep sedation to make sure that the patient does not suffer anymore.

“And that’s why I’m saying that you have to increase the dosage proportionally. Of course, you shouldn’t be too frugal; so the patient is still suffering. You have to control the symptoms as quickly as possible, but without the intention of hastening death” (Jo, coordinating and advisory physician)

Sam, researcher: *“A recurring element in the guidelines is that you adapt the dosage to the condition of the patient, thus don’t sedate more than is absolutely necessary. What are your thoughts on that? That you adapt the dosage to, for example, the level of pain, the expressions on the patients’ face for example? Or perhaps it is better to induce a sort of coma ‘Now we’re sure that the patient isn’t suffering?’”*

Freya, nurse: *“Of course, since you never know if the patient is still experiencing pain ...”*

Babette, coordinating nurse: *“Making the correct adaptation to the condition isn’t easy”*

Frank, head nurse: *“But what’s the use of finding the exact limit, what’s the use of it? If the intention is that he ...”*

Babette, coordinating nurse: *“Because otherwise it goes much faster, then it will go much faster.”*

Frank, head nurse: *“But that’s clearly where we are heading?” [...]*
“I ask myself ‘How are you going to determine that? That fine line, just enough, but not too much?’”

The dosing of sedatives is intertwined with the clinician’s intentions. Often, focus group participants referred (explicitly) to intentions of clarifying that the goal of CSD is to relieve suffering and to provide comfort—not to hasten death. But they are willing to administer large doses of sedatives to control the suffering, even if this involves the risk of hastened death.

“That’s why intention ... I find that it remains important. Intention determines how far you go. Intention determines dosage, the types of medication. So then I say, if you want to carry out that intention ... Ok, if it’s a lot, it’s a lot! If he eventually dies from it, then luck is not on your side, but the intention was symptom control.” (Thor, general physician)

However, the effect of a hastened death is not considered as an untoward effect by some physicians. In addition to the basic intention of alleviating suffering, some physicians (secretly) hope that the patient will die from the administration of sedatives.

“You first try to control the suffering, but—I’m sorry—a hastened death is a welcome side-effect. Is there a theoretical difference? I dunno, but it comes in handy.” (Mark, general physician)

Toward the end of the dying process, clinicians are inclined to administer larger doses of sedatives, with an underlying (co) intention of hastening death.

Hanna, nurse: *“I think that when you’re at the very end, that you’re more inclined to say ‘Ok, I’ll be a little quicker on the draw’. That’s what I think, that I would administer more sedatives.”*

Sam, researcher: *“Do I understand you well? That you are saying—when it’s really almost the end—if we give something more now, it will all be over faster? Is that acceptable?”*

Hanna, nurse: *“It’s not really about speeding things up, but ...”*

Bauke, head nurse: *“Yeah but still, it comes down to the same thing ‘The sooner that their suffering ends ...’ In the end, it’s the same thing.”*

4. Discussion

The purpose of this study was to explore and describe the circumstances under which nursing home clinicians consider continuous sedation until death (CSD) to be justified. All clinicians in our study consider CSD an appropriate intervention for the relief of refractory suffering, even if this suffering has a psychosocial or existential nature. In principle, nursing home clinicians would restrict CSD to patients with a limited life expectancy, although they find this hard to estimate. Combining CSD with artificial nutrition and hydration is considered to be an ethical contradiction. Respecting the patient’s wishes is a matter of major concern in deciding for CSD. However, dementia frequently makes it impossible to obtain informed consent, and impedes the evaluation of suffering as well. The main objective of CSD is to provide a comfortable context for dying, even if this means the hastening of death. Finally, during the administration of CSD, physicians and nurses often feel pressure from the patient’s family to hasten death.

By conducting focus group interviews with nursing home clinicians, we were able to reveal the complexity of the situations in which these professionals have to make decisions about CSD. We organized the focus groups within the nursing homes so that each group consisted of clinicians who regularly meet each other to discuss and make decisions regarding possible end-of-life measures such as CSD. Hence, we believe that the considerations they expressed in the focus group discussions do not differ significantly from their considerations in clinical practice. The same goes for the focus group with only general physicians, where all participants had known each other for a considerable time, and where they were used to discussing end-of-life issues among themselves. Careful consideration was given to the recruitment of participants in order to maximize the variety and richness of the collected data. The size and religious affiliation of nursing homes were taken into account for the sampling plan, because of the possibility that these factors may result in different attitudes and knowledge among clinicians, e.g. through the prevalence and content of written policies on end-of-life care. However, we identified no significant differences between the different focus groups. In three out of six focus groups, physicians and nursing home staff were questioned separately, to avoid the possibility that the presence of the physicians would influence the responses of nursing home staff, or vice versa. Once again, the data analysis did not reveal significant differences between the mixed and the separate focus groups. Nevertheless, despite these measures, it cannot be ruled out that social desirability may have influenced the responses. Additionally, even without this type of bias, the gathered opinions are not necessarily reflective of the actual behavior of the focus group participants in clinical practice. Lastly, it should be emphasized that the aim of this study was not to obtain representativeness in the quantitative sense, but to collect rich and detailed information about all possible considerations of nursing home clinicians until saturation was reached.

Our findings will contribute to a better understanding of the non-adherence to guidelines for CSD, which was identified in previous research, and which has raised many concerns about the proper use of CSD in end-of-life care.^{8,12,13} At first glance, the opinions of nursing home clinicians seem to be basically in line with important guideline elements such as refractory suffering, life expectancy, patient autonomy and the proportional administration of sedative drugs. But further questioning and investigation revealed multiple factors that complicate care situations in nursing homes, and that make it difficult (and frequently impossible) to comply with guideline criteria. Additionally, some clinicians expressed (ambiguous) considerations that may raise some matters for concern.

All focus group participants consider CSD an appropriate intervention for managing refractory suffering, which is in line with all published guidelines on CSD. However, CSD is also found to be justified in cases of existential suffering. This is not an obvious finding. There has been significant disagreement in guidelines and position papers over whether CSD is justified for relieving refractory suffering that can be characterized as 'existential', i.e. suffering that is not marked by physical symptoms. For example, the American Medical Association has published a position statement that explicitly precludes CSD for relieving existential suffering.¹⁴ This is in contrast with other professional organizations, such as the Royal Dutch Medical Association or the Federation Palliative Care Flanders, which find CSD an appropriate measure for managing existential distress.^{5,6} Some organizations, such as the National Hospice and Palliative Care Organization in the United States, find themselves unable to reach agreement on this topic.¹⁵ The European Association of Palliative Care only allows CSD in cases of existential suffering after repeated trials of intermittent sedation.¹⁶ Our findings correspond with observations from a previous qualitative study, where some physicians indeed mentioned that they might be willing to administer CSD to relieve existential suffering—provided that they would fully understand and empathize with the suffering.¹⁷ Nevertheless, evaluating existential distress is quite different from evaluating physical distress. The severity of existential distress may be very dynamic, which makes it difficult to establish that this distress is truly refractory.¹⁸ It may be no surprise that there are no simple and clinically oriented evaluative methods available regarding existential suffering.¹⁹ The clinicians in our study also emphasized that the patient is the one to determine when suffering (both non-physical as well as physical) becomes intolerable and conventional measures have failed. A Norwegian study among nurses reported the same finding.²⁰ However, approximately 65% of nursing home residents in Flanders die with dementia.²¹ The respondents in our study stressed that in such cases it is typically impossible to involve patients in the decision-making process. In addition, dementia may also impede the evaluation of suffering, especially when the patient has become fully incapable.

Generally, clinicians in nursing homes would restrict CSD to patients with a limited life expectancy. This is also in line with all published guidelines, which stipulate that CSD is only justified for patients who are imminently dying, or who are expected to die within 2 weeks. This restriction probably relies on the assumption that CSD would otherwise amount to physician-assisted death because death is (intentionally) hastened—especially in cases where artificial nutrition and hydration are withheld.²² Nevertheless, this important restriction is found to be difficult to turn into practice. The focus group participants in our study expressed that it is often hard to estimate the life expectancy of nursing home residents at the end of life. Sometimes, clinicians are genuinely surprised to see their patients living much longer than expected. This seems to be in contrast with findings from a prospective cohort study in Dutch nursing homes, where physicians tended to overestimate the survival of their patients. Their predictions were only accurate when death occurred within 0–7 days.²³

All the respondents emphasized that respecting the patient's wish is a matter of major concern in the decision-making process, which is congruent with all the published guidelines for CSD. Nonetheless, as mentioned before, most nursing home residents suffer from dementia. At the end of life, many of these patients are not competent enough to be involved in the decision-making process. If no advance care planning has been undertaken, clinicians may consult family members to have a better idea of the patient's wishes. But this brings along potential problems, since nursing home clinicians frequently feel pressured by the patient's family to institute either life-prolonging treatments or to hasten

death. Regarding advance care planning, as a possible solution for such problems, it must be noted that advance directives are not widespread among nursing home residents in Flanders. Research has demonstrated that only 5% of nursing home residents have documented advance directives.²¹ Furthermore, most advance directives embody the refusal of hospitalization or life-prolonging treatment; only 0.2% of the nursing home residents in this study had documented their wishes for CSD in an advance directive.

Guidelines on CSD stipulate that the doses of sedative drugs should be titrated, i.e. proportional to the degree of suffering, in order to reduce the risk of hastening death. Nevertheless, many focus group participants stated that titrating sedatives in very old patients with dementia is not self-evident. Additionally, several clinicians see no argument for finding the fine line between underdosing and overdosing. They find it justified to significantly increase the dosage in order to ensure that suffering is rapidly alleviated; knowing that at the same time death will probably be hastened. In general, according to the respondents in our study, the objective in CSD is to relieve suffering, not to hasten death. However, after further questioning and examination, this claim appears to be somewhat ambiguous. Although all clinicians declare that their intention is to control suffering, several of them acknowledge that the hastening of death is a welcome side effect. At the end of a dying process, co-intentions to hasten death may be involved, resulting in larger doses of sedatives being administered. This is in line with several self-report surveys, where significant proportions of nursing home physicians declared having used CSD with the (co-)intention of hastening death.^{7,24,25} This suggests that CSD sometimes amounts to 'slow euthanasia'; the administration of sedative medications with the intention of hastening death gradually. In an Australian qualitative study among general practitioners, the respondents stated that there is a 'grey area' between palliation and euthanasia, where both a hastened death and relief of suffering are desirable. The authors found it likely that a spectrum of practices of 'slow euthanasia' are being used, depending on several factors, including not only the attending physicians, but the nursing staff and families concerned.²⁶

5. Conclusion

Refractory suffering, limited life expectancy, and respecting patient autonomy are considered essential elements in deciding to CSD. However, multiple factors complicate the care of nursing home residents at the end of life, and often hinder clinicians from putting these elements into practice. Dementia is a major complicating factor, since it impedes the evaluation of suffering and the involvement of the nursing home resident in the decision-making process. Other important complicating factors relate to the estimation of the resident's life expectancy, and the experienced pressure from the resident's family to hasten death. Lastly, the clinicians' considerations regarding the dosing of sedatives and the underlying intentions are divergent; the ambiguity in several opinions raises matters for concern.

Nursing home clinicians may benefit from more information and instruction about how to manage CSD in the complex care situations which typically occur in nursing homes. This study highlights the need for more attention to advance care planning in nursing homes in Flanders, in order to safeguard the patient's autonomy at the end of life. Another key point to improve future practice concerns the ongoing development and refinement of guidelines on CSD. Such guidelines are preferably developed or refined in close collaboration with the nursing home sector in order to more concretely address complex issues such as estimating the life expectancy of very old patients (with dementia), determining the refractory nature of their suffering, or the dosing of sedative drugs.

Disclosures and acknowledgments

This study was supported by a grant from the Fund for Scientific Research, Flanders, Belgium (G080309N). This funding source had no role in study design; in the collection, analysis and interpretation of the data; in the writing of the manuscript; or in the decision to submit for publication. All authors declare that they have no conflict of interest. We thank Charlotte Benoot for her contribution in the data analysis and Douglas Atkinson (*Interfacultair Departement voor Taalonderwijs, Vrije Universiteit Brussel*) for his linguistic help in preparing the manuscript.

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